



Children With Special Health Needs

Needs Assessment

A Research Study Conducted On Behalf Of:

North Dakota Department of Human Services

Summer 2004

Research Study Conducted By:

Marketing & Advertising and Business Unlimited, Inc.

doing business as Agency MABU

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Acknowledgements

The North Dakota Department of Human Services contracted with Marketing & Advertising Business Unlimited, Inc., (dba Agency MABU) to conduct a market research study in the summer of 2004. The purpose of the study was to assess the needs for children with special health care needs and their families.

The research team extends sincere thanks to representatives from the North Dakota Department of Human Services, Children's Special Health Services Unit. Special appreciation is presented to Tamara Gallup-Millner, Unit Director, and Terry Bohn, SSDI Coordinator, for providing guidance, direction and support throughout the entire research process.

The research team also acknowledges the individuals who participated in the research study by attending focus group sessions, completing written surveys and taking part in telephone interviews. The data gathered through these research methodologies were used to prepare the findings and recommendations for this study.

Funding for this project was provided through the North Dakota Department of Human Services. For more information or to receive copies of this report, contact:

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Respectfully submitted,

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Conduct Of Study

In the Spring of 2004, Marketing & Advertising Business Unlimited, Inc. (dba Agency MABU) was commissioned by the North Dakota Department of Human Services to conduct a market research study to assess needs relating to children with special health care conditions, especially chronic illnesses.

The primary objective of the study was to obtain qualitative information from pediatric providers and families of children with special health care needs (CSCHN).

Agency MABU used a variety of research methods to gather data including:

- A series of six (6) focus group sessions with parents of children with special health care needs.
- A mail back survey of pediatric providers
- A telephone survey of pediatric providers

These research methodologies which were employed by Agency MABU are described in the following sections:

FAMILIES OF CSHCN: FOCUS GROUP SESSSIONS:

In June 2004, *Marketing & Advertising Business Unlimited*, Inc. (doing business as Agency MABU) conducted a qualitative research study to assess needs relating to children with special health conditions.

The project included six (6) focus group sessions held throughout the state of North Dakota. Mike Mabin, owner of Agency MABU, served as the lead researcher in developing the research plan and facilitating the focus group sessions. Mabin was assisted by Sarah Franke, Tiffany Mittleider, Amanda Bakkedahl and Annette Tait, MABU employees who coordinated various aspects of the project including recruiting focus group participants, arranging the focus group sessions and documenting results.

Focus Group Sessions Continued:

From June 1 - 14, 2004, Agency MABU conducted a total of six (6) focus group sessions with up to 12 participants in each group. The sessions were held at the following locations and times:

Bismarck

Date: Tuesday, June 1
Time: Noon – 1:00 p.m.
Place: St. Alexius Medical Center (Telemedicine Conference Room)
Status: 12 registered, 11 participated

Note: 8 participated from Bismarck and 3 participated via teleconferencing from Dickinson and Ashley

Minot

Date: Thursday, June 3
Time: Noon – 1:00 p.m.
Place: Trinity Health Center
Status: 12 registered, 11 participated

Bismarck - UTTEC

Date: Monday, June 7
Time: Noon – 1:00 p.m.
Place: United Tribes Technical College (Jack Barden Center)
Status: 9 registered, 4 participated

Williston

Date: Tuesday, June 8
Time: Noon - 1:00 p.m.
Place: Mercy Medical Center
Status: 12 registered, 12 participated

Fargo

Date: Friday, June 11
Time: Noon - 1:00 p.m.
Place: MeritCare
Status: 12 registered, 10 participated

Grand Forks

Date: Monday, June 14
Time: Noon - 1:00 p.m.
Place: Altru Health
Status: 8 registered, 6 participated

Focus Group Sessions Continued:

Focus group participants were recruited through a variety of means including, but not limited to, the following strategies:

1. News release sent to all media statewide
2. Letter and flyer to participating hospitals/clinics (pediatric and family practice)
3. Phone calls to health-related associations
4. Phone calls to family organizations
5. E-mail message to Human Service case managers
6. Cover letter and flyers to daycares statewide
7. E-mail, letter and flyers to Community Resource Coordinators
8. Mailing to Special Education Units

Several days prior to each focus group, participants were contacted by Agency MABU to confirm their attendance. Each focus group session lasted approximately one and a half hours, and participants received lunch and an incentive payment of \$25. Mike Mabin served as the discussion facilitator. He used a written discussion guide to assure specific topics were addressed. Agency MABU staff documented the comments in writing. Recordings were also made on videotape and used as reference for capturing feedback from the focus group participants. Participants were also invited to complete a written questionnaire (based on the discussion guide) to document any feedback that they preferred to share in writing rather than verbally.

PEDIATRIC PROVIDERS: MAIL-BACK AND TELEPHONE SURVEYS:

Agency MABU utilized two proven research methods to assess the capacity of pediatric service providers throughout the state.

First, a series of 40 telephone interviews were conducted with a minimum of one (1) and maximum of three (3) representatives from each of the pediatric professional groups identified in the request for proposals (RFP). The names and contact information for prospective interviewees were obtained primarily through professional membership associations; however, yellow page directories and organizational websites were also used as resources in identifying telephone survey respondents. Using a stratified random sample process, the selected individuals represented the geographic diversity of the health care system in North Dakota.

Secondly, a written questionnaire was direct mailed to a simple random sample of 1,000 representatives from a combined list of pediatric professional groups identified in the request for proposals (RFP). The mailing included a cover letter, questionnaire and postage paid return envelope. The questionnaire was a condensed version of the telephone survey, and was designed to be completed easily and quickly by survey respondents. A total of eight (8) closed-ended and five (5) open-ended questions were included on the questionnaire. By keeping the survey brief, a goal of securing a 12%-15% response rate was established.

A total of 308 written surveys were completed and returned within the established deadline. This represents a 31% response rate. Thus, it was determined that the results of the mail-back study represents a margin of error of plus or minus five (5) percentage points from the total population due to the relatively high response rate and homogenous

nature of the sample group. This means that if 95% of the respondents to the survey answer “yes” to a particular question, somewhere between 90% and 100% of the total population would answer the same.

The survey instrument used for both the telephone and mail-back questionnaires included questions to assess perceptions of pediatric providers as identified in the RFP (e.g. barriers and challenges).